# Using evidence for advocacy impact

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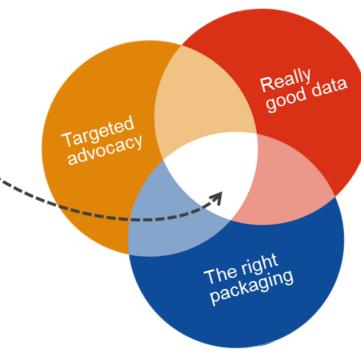
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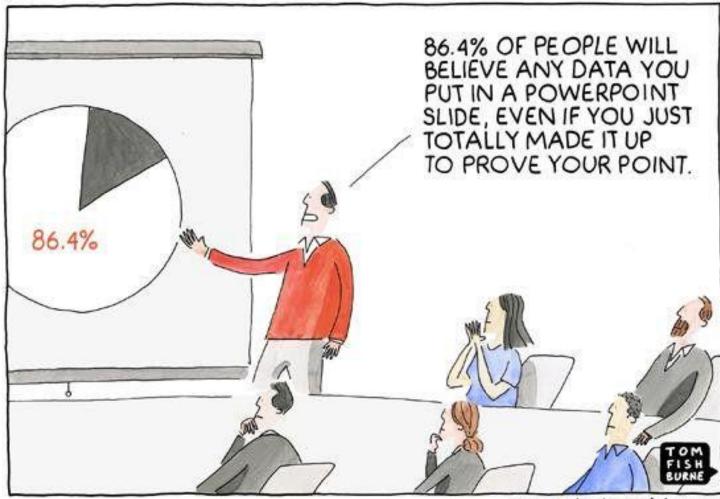
@ZPWLC

#### **Evidence-based advocacy – What is it?**

Systematic and targeted collection, interpretation, generation and deployment of sound data and information, presented and used in **patient advocacy with an objective in mind**.

Advocating in a targeted, evidence-based, welleducated and professional manner, and measure impact and outcomes of what we do.





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Why use evidence?

Credibility



## Why use evidence?

## Understanding

#### Responsibility on the patient community to use EBA to drive change...

UK based patient experience survey of 2,329 leukaemia patients from Leukaemia Care.

Used to identify unmet needs and to inform:

- Organisational strategy
- Campaigns e.g. patient issues
- Evidenced access arguments to inform NICE submissions
- Publish at scientific conferences



#### Leukaemia Care Living with Leukaemia

2018 Report



www.leukaemiacare.org.uk

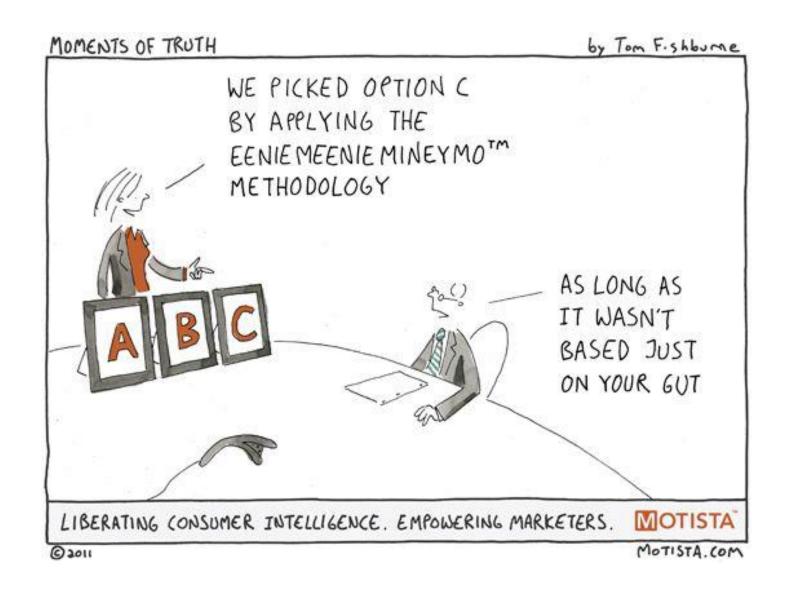
## How to use evidence..

- 1. Listen to the evidence
- 2. Act on the evidence

**DO NOT** use evidence just to back up your existing point of view



I see here that I'm right about everything.



## Methodology is key...

#### Does your evidence show what you think it does?

- Did you ask the right question?
- Did you ask the right people?
- Did you ask enough people?
- Is your conclusion what the data shows?
- Is it statistically valid?

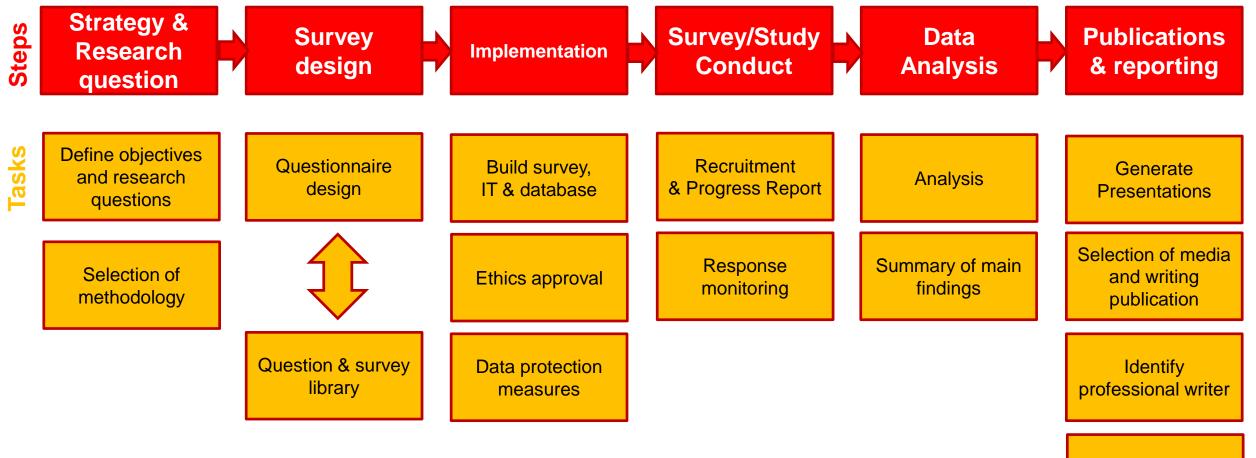


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#### Key elements of evidence generation for EBA

WECAN Academy





Write publication

Slide from WECAN training course on Evidence-Based Advocacy

# Be clear from the start how you want to use the data

YOUR PURPOSE DETERMINES WHAT TYPE OF PROJECT TO RUN...



## Setting your strategy and research question?

Strategy &

Research

question

Define objectives

and research

questions

Selection of

methodology

Step:

sks

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At the **outset** of any project, and at any point you make significant **changes** to your plans, ask yourself:

- What am I trying to achieve?
  - What is your desired advocacy impact?
  - What do you want to show, and to whom?
  - What evidence do you need to back up your work?
  - What is already known and what do you need to collect?
  - What types of evidence will be most effective with your stakeholder group?
  - What is your analysis strategy?
- Everything flows back from this e.g. type of evidence generation, publication decision – consider undertaking strategic review

## What is already known?

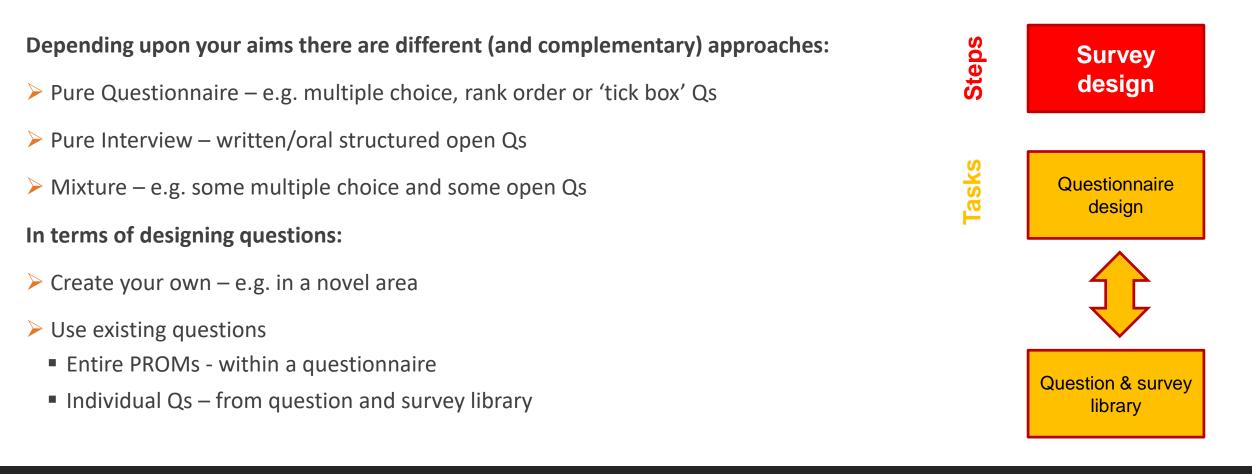
#### As a general rule of thumb...

Use to help identify:

- 1. What type of evidence generation
- 2. What to collect evidence on?
- 3. Or whether you even need to collect any?
- Thinking here about what is known to other researchers
- And what is only known to patients and/or advocates



## Considering type of evidence generation (e.g. survey)



#### Slide adapted from WECAN training course on Evidence-Based Advocacy

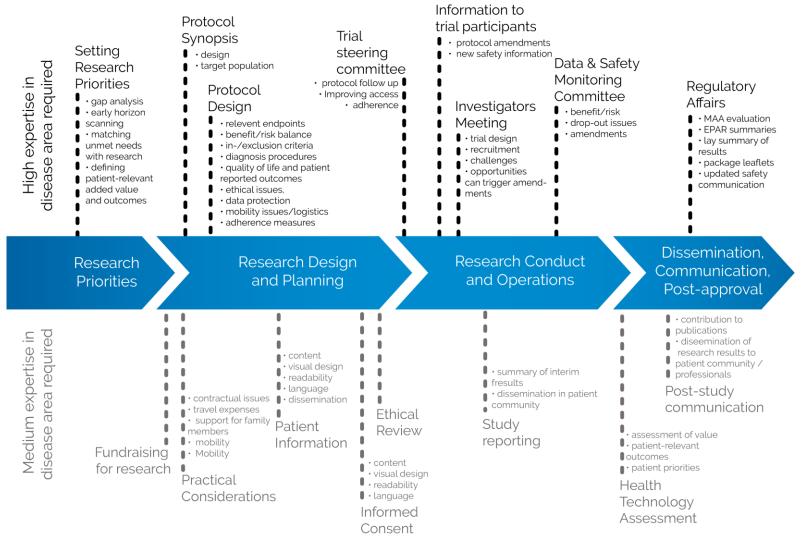
## Don't just generate evidence for the sake of it!

BE CLEAR AT THE START ABOUT WHAT DATA YOU NEED AND HOW IT WILL BE USED



#### Patient involvement in medicines R&D

Patients should also be involved in external evidence generation...



## Case Study: Living with leukaemia

LEUKAEMIA CARE



## **Project Overview**

Aims – Exploring UK leukaemia patient experience

#### Topics – Following the journey from diagnosis onwards

#### Testing – To refine the content



Comparability – between annual versions



#### Patient Survey

This questionnaire is about your care and treatment for a blood cancer. Its purpose is to provide information, which can help the NHS and Leukaemia CARE monitor and improve the quality of health services for future patients with blood cancer.

Taking part in this survey is voluntary. Published reports will not contain any personal details.

#### Who should complete the questionnaire?

The questions should be answered by you, as the person who has been treated for a blood cancer. If you need help to complete the questionnaire, the answers should be given from your point of view – not the point of view of the person who is helping.

#### Completing the questionnaire

For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't womy if you make a mistake; simply cross out the mistake and put a tick in the correct box.

#### IMPORTANT INFORMATION

To make sure the information we collate is useful, we need to collect some personal details from you and access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the care and treatment people receive. These statistics will be used to compare the differences in care and treatment by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

 Your personal details and relevant health information can be held and used by an organisation contracted to Leukaemia CARE to analyse the data.

 Your personal information will be handled securely and anonymised after analysis and before any publication.

 Your personal information will not be released by anyone working on behalf of Leukaemia CARE unless required by law or where there is a clear overriding public interest.

 You can withdraw the information you give Leukaemia CARE in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire, please call the FREEPHONE helpline number on 0600 783 1775

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## Methodology: Cohorts

#### CPES

 Patients identified using the NHS CPES survey

#### Leukaemia Care

- LC Database
- Had a valid postal address (for paper survey)

#### Anonymous

Online link
Wider blood cancer community
LC email consent

## Different output types

#### **Reports and Presentations**

#### **Scientific Publications**

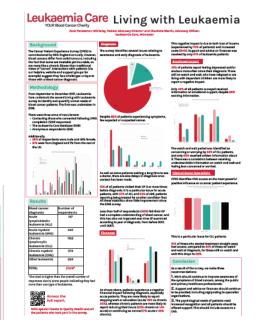


www.leukaemiacare.org.uk



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#### + Journal articles

#### As a starter for follow-up projects...

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### Leukaemia Care Living with Leukaemia

2018 Report



www.leukaemiacare.org.uk

National Institute for Health and Care Excellence



### How can patient groups use RWE in their activities?

EXAMPLE FROM LEUKAEMIA CARE (UK)





## Leukaemia Care Living with Leukaemia

2018 Report



www.leukaemiacare.org.uk

## Defining Unmet Needs

Identify: What are the issues to focus on

#### Measure

- Quantify issues (e.g. the % of patients experiencing)
- Differences between particular groups. such as demographics, cancer type, regions, time

**Solutions**: Create a set of recommendations to address

**Further Questions** - Is there anything you need more evidence on?



## Organisational Strategy

#### Strategic plan for Leukaemia Care 3 years – 2019 to 2022

Presented to the Trustee Board

esented to the Trustee Boar 23 January 2019



How are you going to address the unmet needs?

#### **Questions to think about:**

What are you already addressing? What should you do differently? What do you need to do more of? What are you not doing? What can you **NOT** do? What should be worked on by others?

#### **Collect Further Evidence**

Use Key Performance Indicators (KPIs) – to measure outcomes and impact Collect data and compare – e.g. performance across years

## **Developing New Services**

One you have identified an unmet need to focus on...

- Designing the service what exactly do you need to address?
- Use evidence for your funding application
- Use feedback to refine existing services
  - Use Key Performance Indicators (KPIs) to measure outcomes and impact
  - Individual feedback from users (e.g. survey)
- Consider running a small PILOT to show it works?



## Campaigns – Awareness and Early Diagnosis

#### **Understand your audience**

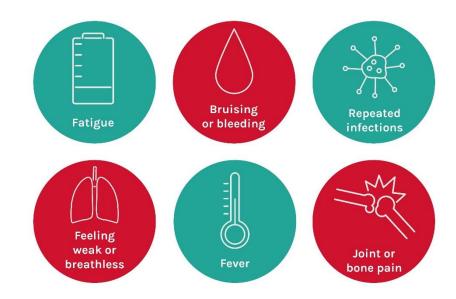
- Public v Patient are you targeting a specific demographic?
- What does the audience already know?

#### **Use Evidence**

- Your own (e.g. survey)
- External (e.g. NCIN Routes to Diagnosis)

#### Consider your message

- What does the audience need to know?
- Where to focus? e.g. MPN, blood cancer or cancer





### Campaigns – Patient Issues

- Using evidence to develop and run campaigns to address specific issues
- **Audience** Patients? Clinical community?
- Evidence Tailor to look at differences? Can you do a specific survey? Or breakdown of an existing survey?
- Message What are you trying to change?

#### Example: 'Watch Wait Worry' campaign

- We developed:
  - Evidence Report for clinicians
  - Supportive guidance for CLL patients on watch and wait
  - Social media campaign
- Poster at EHA on the emotional impact of watch and wait for CLL

## Access: Health Technology Appraisals

- Different HTA processes have different opportunities for patient organisations to get involved
- In most cases the consideration of patient perspective is qualitative, so it is difficult to understand the impact on decision making
- You can create quantitative evidence (e.g. patient surveys), but at present there is no mechanism for the inclusion of such evidence

- Focus on:
  - Influencing the areas that influence decision making (e.g. cost-effectiveness)
  - Impact not involvement
  - Explaining existing evidence (e.g. trial) and the benefit from a patient perspective

National Institute for Health and Care Excellence



